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ABSTRACT

The paper discusses the role of the Child Life Worker as a member of a multidisciplinary team in the rehabilitation of cancer patients and their families when children are involved. It is noted that the concepts can be applied to any chronic pediatric illness or handicapping condition. (Author/SBH)

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HELPING THE SICK CHILD LIVE WITH CANCER: THE ROLE OF THE CHILD LIFE WORKER IN AT-HOME TEAM REHABILITATION

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Abstract:

The Cancer Center, Inc. of Northeast Ohio, with headquarters in Cleveland, has developed a multi-disciplinary team approach to the rehabilitation of cancer patients in the home setting. This demonstration project is funded by the National Cancer Institute* for a three-year period and consists of a Project Director, three Social Workers, two Public Health Nurses, a Physical Therapist, Occupational Therapist, Vocational/Educational Counselor, Health Educator and Child Life Worker.

This paper discusses the role of the Child Life Worker in the rehabilitation of cancer patients and their families when children are involved, but the concepts can be applied to any chornic pediatric illness or handicapping condition.

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HELPING THE SICK CHILD LIVE WITH CANCER: THE ROLE OF THE CHILD LIFE WORKER IN AT-HOME TEAM REHABILITATION

Paulette Tharp*

The diagnosis of cancer affects every family member and the At-Home Rehabilitation Team of the Cancer Center, Inc. of Northeast Ohio is dedicated to total family care. Every newly diagnosed cancer case in Cuyahoga County is a potential At-Home Rehabilitation Team case with referrals coming from four greater Cleveland hospitals participating in this pilot project.[1] As of May 31, 1978, 411 cases were screened with hospital personnel with 250 being accepted into the program.

The Team's goals are to help ease the transition from hospital to home; aid the patient and his family to understand and accept the illness; plan and implement programs for rehabilitation; and re-integrate the patient and family to normal living, insofar as possible.

The attending physician, hospital social worker, or nurse introduces the Team program to the family while the patient is in the hospital, and it is up to the family to decide whether or not to accept the Team's services. Only five families have refused but indicated that if they needed help they would call. The Team's Social Worker arranges for the initial home visit and acts as the Team's Coordinator. The Social Worker assesses the family's needs and reports to the entire Team at weekly care conferences. If there are children involved in the case as patient, sibling, or offspring, the Child Life Worker member of the Team will accompany the Social Worker on home visits. If the child/patient is of school age, the Vocational/Educational Counselor Team member will be asked to be part of the Team. If the child has been hospitalized for a long

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time or has suffered an amputation, the Physical Therapist will be asked to design an exercise program or to aid in managing a prosthesis and teach ambulation. Depending upon the nature of the cancer, the Team Nurse may be required. Thus the Team assembles and re-assembles itself according to the needs of the patient and family, and the therapeutic program of the physician.

The Pediatric Cancer Patient

While the separation trauma of hospitalizing a gravely ill child is severe, another crisis is created when the patient is discharged and the family must now care for and relate to a "different" child at home. Radiation therapy, chemotherapy, or surgery may have "altered" the child and the family experiences a multitude of conflicting emotions such as relief that the child is out of the hospital and optimism about the future, along with feelings of anxiety, anger, guilt, and fear. Many parents worry about caring for the child at home: will they know if something is wrong?; do they need special equipment and can they afford it?; will they be able to integrate the child back into the home and school?; what will they tell the other children, relatives, friends?

Early in the program the family is assured that their feelings are universal and normal and that the Team is its advocate, and through the Team the family has a direct link with the family physician, the hospital, and other community services. Family members are encouraged to articulate their concerns and to express them to the appropriate Team member.

Answering questions posed by the parents about their sick child is difficult, but responding to a young patient's questions is more so. The questions may not always be explicit and, furthermore, the child needs answers to questions he may not even be able to formulate. For example, Paul, a four-year old with neuroblastoma (a cancer of nerve tissue), asked: "What happens when someone dies?" Implicit in the question but not directly expressed was: "Am I going to die and

what will happen to me when I die?" Dr. Elizabeth Kubler-Ross in her researches into the dying process, says that many children try to protect their parents by not asking searching questions, yet these questions trouble them and they need answers. It takes all the skill, training, and sensitivity of the Child Life Worker to unravel the questions and respond to them satisfactorily. A child may think that he has done something wrong and his cancer is the result, or he may fear that his disease is contagious and other family members will become ill because of him. He may have worries about how his family and friends will relate to him; whether he can return to school; whether he will grow up and lead a normal life.

Children, like adults, are reluctant to express their innermost feelings, especially to non-family members, but once questions are answered honestly, the children do not manifest anxiety as much as when the true nature of their condition is kept hidden. It is fear of the unknown that is the most troubling and gives rise to misconceptions and fantasies. Answers to the questions of a child with cancer (or any other illness, for that matter) should be honest and direct, phrased in terms the child can understand, and answered in context.

The Child LIfe Worker of the At-Home Rehabilitation Team has amassed a collection of materials (many of which I designed myself) which are geared to various age levels. These materials are used to answer questions and to explain what cancer is and what to expect from the course of treatment. Coloring books telling a story about cancer, illustrations and models of the human body, dolls with detachable limbs and removable hair, specifically designed board games and puzzles can graphically teach and serve as stimuli for conversation and as points of reference. Models of radiation and chemotherapy help a child understand and prepare for treatment procedures.

Chemotherapy, for instance, is quite an ordeal and has many side effects such as hair loss, nausea, weight loss, and mouth sores. The treatment may cause

changes in appetite or result in no appetite and thus nutrition becomes a vital part of the patient's rehabilitation. Feeding a sick child is a challenge for the best of cooks and the most devoted care giver. The Team's Public Health Nurse, (trained in nutrition) will teach both the patient and the family the need for good nutrition and will show the primary care giver how to prepare appetizing, nutritious, simple meals. The National Dairy Council[2] has educational materials suitable for children in the form of food cut-outs and booklets, and recipes and helpful hints for the proper food preparation. Teacher Concepts, Inc. has designed a board game called Super Sandwich[3] explaining calories, carbohydrates, proteins, and the daily requirements which is fun to play and reinforces good eating habits.

Another side effect of chemotherapy is muscle weakness. The Physical Therapist joins the Team to design an exercise program suited to the child's physical level and will incorporate play activities such as bicycling into the exercise program, if possible. There are many activities that the Child Life Worker and the Physical Therapist can introduce to stimulate sensory motor abilities such as modeling in clay or play dough, finger painting, stringing large beads, stacking blocks, etc. Play/exercise activities need not be dependent upon purchased materials; many items in the home can be utilized and only the imagination imposes limits. Nuts and bolts, egg beaters, step ladders, stairs and furniture can be made to serve as exercise equipment with a little ingenuity.

Fear of doctors and nurses is often expressed and sometimes overcome by letting the child explore a play physician's black bag and its contents filled with a stethoscope, syringes, tongue depressors, etc. Educational material like puzzles depicting doctors, dentists, and nurses at work help to overcome fears and encourage good hygiene habits. Ongoing routing health maintenance is important to rehabilitation such as getting new glasses or visiting the dentist. In addition they are psychologically beneficial as they are future-oriented and are not related to the cancer. Books which the child can either read himself or can be read to

him can help answer his questions or overcome his fears and anxieties. Libraries are wonderful resource places and very often have slides, films, and records for rental which are educational or simply entertaining.

A positive self-image is important for any child, especially one that is seriously ill. One child became withdrawn and avoided peer activities after she had lost all her hair because of chemotherapy. Until the Team was able to locate a source for child-sized wigs, adult hairpieces had to be cut down to fit and the result was uncomfortable and far from satisfactory. But when the child had her own light-weight, attractive wig, she looked forward to returning to school and playing with her friends.

The Child Life Worker has large flannel pieces of body parts and playing with these pieces stimulates conversation about how children view themselves. The need for good grooming and good hygiene is discussed as the pieces are handled. Efforts to encourage children to care about their health and appearance must be reinforced by other family members, and all Team members are involved in these endeavors.

Playing with peers and siblings is essential to the patient's social growth and mental development and the well children in a family usually enjoy playing with the sick child's special toys and games. This is a time when the Child Life Worker observes the sibling's own problems.

The Siblings

The Child Life Worker of the At-Home Rehabilitation Team must be alert to the effects that the diagnosis of cancer has upon the children in the family, whether the patient is a brother or sister or whether it is the mother or father who is ill. Family discipline and controls need to be imposed and maintained both for the patient's benefit and for the benefit of other members of the family. The sick child should not be treated so specially that the siblings wish that the siblings wish that they were ill, too. It is hard for parents to refrain

from doting upon an ill child, but it is important for them to understand that siblings get jealous or angry because of the many demands a sick child imposes on parents. Trips back and forth to the hospital or physician may be viewed as "special times" with Mom or Dad which the well children are denied. Hyperactivity can be a manifestation of a resentful child. One family's six-year old daughter's physical activity increased markedly subsequent to her five-year old sister's cancer. Her mother said that the six-year old "... jimps from one activity to another and can't sit still. She says mean things to her sister, father, and me and is cruel to her pet kitten. She always was an active child, but this is too much!"

Home visits to this family were designed with both girls in mind. The patient and her sister were encouraged to participate in activities which emphasized self-image and the expression of feelings. They shared these feelings with one another and with their mother at the close of each visit. The girls had the opportunity to experience a special time together and with their mother. The six-year old's overactive behavior had been the result of feelings of being left out and ignored and when her needs were satisfied, she calmed down and did not demand as much extra attention.

Sometimes a sibling may become withdrawn or show evidence of regressive behavior. These may be symptoms of fears such as: "Am I going to lose all my hair like Michael?" "Is my brother going to die?" "Will I get cancer, too?" Questions like these may or may not be put directly to the Child Life Worker but will be asked of the parents. The Child Life Worker attempts to brief the parents about questions that might be raised and offers possible answers the parent can use when the time comes. There are many good books the Child Life Worker can recommend which help when the parents are at a loss for words.[4]

The Parents

The children of parents with cancer are seriously affected emotionally by

their parent's disease. Since the Team works with the entire family, the Child Life Worker is asked to be a friend to these children. The parent with cancer is often so overwhelmed by his own emotions that he has difficulty in explaining his condition, treatment, or changes that the family is experiencing. For example, a mother with lung cancer was unable to talk to her ten-year old son about her illness. Derrick was normally a quiet boy but became more and more withdrawn as the disease progressed. The Team made up a story book with line drawings of Derrick and his family (drawn by the Health Educator) which told about his mother's illness, explained the treatment procedures, and incorporated words expressing love, fear, anger, worry, and hope. It was Derrick's very own book, created especially for him, and it served to help him understand that his feelings were normal.

Another child was able to ask direct questions: "Why did you make mother mark on herself?" (This was in reference to the delineation a patient has for radiation therapy.) Other questions about her mother's mastectomy were: "Why did they cut it off? Where did they take it?" The questions were carefully written down in the presence of the child and on a later visit, the Child Life Worker brought a viewer with slides showing a picture of the hospital building, the waiting room, laboratory, operating room, the treatment room and slides of normal and abnormal cell growth. This child felt better knowing all the particulars and specific details, but each child is unique and each case is different. The Child Life Worker constantly re-assembles her educational/play materials, creates new ones, and in all ways attempts to anticipate needs and be prepared to answer questions.

Sometimes the family situation does not lend itself to a home visit. In one case, a fifteen-year old girl whose mother was dying of cancer, lived in a household that was in constant turmoil. Visits were set up in the Child Life

Worker's office at the Cancer Center and Kelly came by herself after school. As her mother's condition deteriorated, Kelly's anxiety increased and she desperately needed a respite from the triangle of home, school and office. We visited the Cleveland Health Education Museum which has exhibits on basic body systems and functions, sexual development, and parenting, as well as cell biology and cancer. We discussed her concerns about herself and her mother and talked about the problems confronting adolescents in general. We went to the Cleveland Museum of Art and to the Western Reserve Historical Society, to parks, neighborhood college campuses, and America's ubiquitous hamburger hand-out, McDonald's. Every community has facilities that can be used to conduct meetings when the home environment is not conducive to visits, or when getting out of the sick room atmosphere is essential, especially for restless teen-agers. Dialogue is easier to initiate in the non-threatening, neutral atmosphere of a community resource and libraries, museums, and recreational facilities are excellent alternative locations. A thirteen-year old boy whose mother had cancer, had an alcoholic father who was very disruptive. We arranged for visits outside the home, one time touring a World War II submarine permanetnly docked in Lake Erie. In the course of these outings, we were able to establish a trust relationship and he was able to express concerns he could not talk about at home.

When death finally separates a child from his parent, the Child Life Worker in partnership with the Social Worker remains in touch until she feels that the child has come to reasonable terms with death. Joyce, a highly verbal nine-year old was certain that the cause of her mother's death was a faulty oxygen tank. She had sublimated her real concerns into overly inquisitive questions about the treatment, as if she needed to blame a piece of mechanical equipment for her mother's death. We talked at great length about why her

mother couldn't breathe and how the oxygen helped. Joyce was finally able to accept her mother's loss and had no further need to blame "something."

The finality of death is not easy to accept. Many families obtain the strength they need from their own family supports and religious beliefs. The At-Home Rehabilitation Team offers additional support to enable families to cope with their loss and help them over the grieving period. If it is the wish of the patient and family to die at home, the Team makes every effort to make this possible and provides the appropriate support systems.

The work of the Team has demonstrated that families need help and support in dealing with the physical and emotional problems of keeping a patient at home. As long as the patient is hospitalized or otherwise institutionalized, responsibility rests with other care givers, but at home, the family must cope with the reality of total care. A group of multi-disciplinary professionals whose presence can be relied upon; who offer pragmatic help and information; who help the family resolve emotional conflicts and physical disabilities; and who provide supportive services within the home environment do much to alleviate medical and family crises. The experience of the Cleveland At-Home Rehabilitation Team (which I am a part) can serve as a model in the organization of one type of health care system designed to help families care for seriously ill members in the home setting.

Footnotes

1. The Cleveland, Ohio, hospitals that participated are:

   Rainbow Babies and Children's Hospital of University Hospitals, Inc.
   The Cleveland Clinic Foundation
   Cleveland Metropolitan General Hospital
   St. Luke's Hospital

2. The National Dairy Council, local chapter, Dairy and Nutrition Council, 2475 East 22nd Street, Cleveland, Ohio, 44115, U.S.A.

3. Teacher Concepts, Inc., 230 Park Avenue, New York, New York, 10017, U.S.A.

4. At-Home Rehabilitation Project of The Cancer Center, Inc. of Northeast Ohio, 11001 Cedar Avenue, Cleveland, Ohio, 44106, U.S.A., has prepared an extensive bibliography available on request.